

# THE FIRST COMPETENCY BASED FRAMEWORK IN GENETICS/GENOMICS SPECIFICALLY FOR MIDWIFERY EDUCATION AND PRACTICE

Emma T Tonkin<sup>a</sup>, Heather Skirton<sup>b,c</sup>, Maggie Kirk<sup>a,c</sup>

## Affiliations

<sup>a</sup> Genomics Policy Unit, Faculty of Life Sciences & Education, University of South Wales, United Kingdom

<sup>b</sup> School of Nursing and Midwifery, Faculty of Health and Human Sciences, Plymouth University, United Kingdom

<sup>c</sup> Retired

## Authors

Emma Tonkin PhD BSc (Hons),  
Senior Research Fellow,

Email: [emma.tonkin@southwales.ac.uk](mailto:emma.tonkin@southwales.ac.uk) +44(0)1443 483156

Heather Skirton PhD RGN, Qualified Midwife, Registered Genetic Counsellor.  
Professor of Applied Health Genetics,

Email: [heather.skirton@plymouth.ac.uk](mailto:heather.skirton@plymouth.ac.uk) +44(0) 1752586569

Maggie Kirk PhD, Dip Nurs, RGN, FRCN  
Professor of Genetics Education,

Email: [maggie.kirk@southwales.ac.uk](mailto:maggie.kirk@southwales.ac.uk) +44(0)1443 483074

**Corresponding Author:** Emma Tonkin

**Full postal address:** GTAB213, Genomics Policy Unit, Faculty of Life Sciences & Education, University of South Wales, Glyntaff Campus, Pontypridd, Wales, UK CF37 1DL

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## **Abstract**

This paper details a competency framework to help address the need for structured guidance around genetic and genomic education and training for midwives.

A one-day expert panel consensus meeting was convened to review and revise a previously published joint framework for nurses, midwives and health visitors. Fifteen midwives from practice, management, education and policy and three genetic counsellors (two with midwifery backgrounds) attended. An in-depth knowledge of genetics/genomics was not a requirement. Personal narratives covering a range of experiences across the pre- and post-natal periods were used to stimulate discussion and debate. Identified themes were mapped to the original framework to identify gaps and differences. Inclusion of additional themes into the new framework was voted upon.

All original competencies were found to be valid but required amendment in order to focus specifically on the role of the midwife and the needs of the mother, child and wider family. Revisions have resulted in a framework that is more directive and which addresses the time-critical nature of information-giving, decision-making, testing and referral that are crucial components of midwifery practice. Learning outcomes and practice indicators offer educators and trainers a means of developing student/staff knowledge and skills over time and with increasing experience.

## **Highlights**

- Genomics is an integral component of the maternal and family health care pathway

- This is the first genomics competency framework explicitly for midwifery practice
- Learning outcomes and practice indicators develop over time and with experience
- Competencies are written to accommodate future genomic advances in midwifery
- Genomic competence can improve care, consistency and safety for women and families

**Keywords**

Competency; Midwifery; Education; Genomics

## Introduction

Genetics has become an integral component of the entire maternal and family health care pathway from pre-conception through to the post-partum period. For many pregnant women the genetic component of their childbearing experience may be limited to the advice given regarding folic acid supplementation, diet and lifestyle; taking of family history information during the booking appointment; and information provision and consent for 'routine' antenatal and newborn screening tests. These interventions may not even be perceived as being related to genetics. For other women, more obvious risk factors such as a positive or high-risk screening result, knowledge of an inherited condition in the family or the identification of an unexpected condition during the anomaly scan or at birth, may extend their experience of genetic healthcare. This can include diagnostic testing of the fetus, referral to specialist services, and decision-making around continuation of pregnancy, care planning or termination of pregnancy. While midwives need to utilise their core skills in communication, compassion and ethical care in these situations (Commissioning Board Chief Nursing Officer and DH Chief Nursing Adviser, 2012), they also require core knowledge of genetic concepts that can be drawn on and applied to each specific case.

The complexity of midwifery practice continues to increase as our understanding of genetics and genomics (the inter-relationships of genes and the environment, and the associated ethical, legal and social issues) expands. Scientific findings are translated alongside technological developments, into advances in the clinic. For example newborn bloodspot screening (NBS) is used around the world to detect inborn errors of metabolism and other inherited disorders. Advancements in technology now make comprehensive screening for 50+ conditions possible. In the United Kingdom (UK), midwives are involved in consenting

for and taking of samples, and sometimes in the return of results. Therrell et al. (2015) describe the global variation in provision (ranging from countries with full population screening mandated to those with no or minimal screening) and the complexity of delivering NBS in many regions. Even within Europe the picture is very mixed and is dynamic. In Great Britain for example, four conditions were added to the NBS panel over recent years bringing the total number of conditions currently screened for to nine. Another example of a significant advancements in maternity care, is non-invasive prenatal testing (NIPT) for Down syndrome (trisomy 21/T21) and other common aneuploidies using cell free fetal DNA (cffDNA). Already available within the private sector, evaluation of this technique within the National Health Service, as an alternative to the current options of the combined or quadruple tests, has been recommended (UK National Screening Committee, 2016) and is ongoing.

Midwives will be required to manage such developments in current practices, incorporating the increase in information that needs to be provided to women and their families to support informed decision-making around screening and testing. This professional responsibility is emphasised in the UK policy document *Compassion in Practice* (Commissioning Board Chief Nursing Officer and DH Chief Nursing Adviser, 2012). However, a recent study by John (2016) examining 100 first consultations with midwives (n=16) found that not all women were fully informed about Down syndrome and screening.

Whilst not currently utilised routinely in the newborn period, exome and whole genome sequencing (WGS) is becoming increasingly accessible in a clinical context to confirm clinical diagnoses and identify at-risk individuals. Recognising that such use can inform clinical management and decision making, Borghesi and colleagues (2017), offer a rationale for the

use of whole exome sequencing (WES) in the critically ill newborn infant. Howard and colleagues (2015) discuss the issues and challenges of using this technology within NBS programmes. Their recommendation, endorsed by a number of international organisations, is that a targeted approach to the identification of “preventable or treatable conditions, for which treatment has to start in the newborn period or in early childhood” remains (Howard et al., p.1598). As WGS and other similar advances intersect more frequently with the midwifery role, midwives will need to incorporate them successfully into practice. Ideally, fundamental core knowledge and skills in genetics/genomics should be in place as part of competency attainment during pre-registration education, becoming embedded once in practice and thus provide a foundation to build upon when new clinical situations such as WGS arise.

### ***The impetus for a genetics/genomics framework for midwifery***

In many countries over the last 15 years there have been concerted efforts to drive integration of genetic and genomic healthcare into services. Examples include the UK Government’s White Paper *Our Inheritance Our Future* (Department of Health, 2003) and the more recent 100,000 Genomes Project (Siva, 2015), the US’ Precision Medicine Initiative (The White House, 2015) and Australia’s National Health Genomics Policy Framework (Australian Health Ministers’ Advisory Council, 2017). In the UK, the Department of Health commissioned and funded the development through stakeholder consensus, of a combined genetics competency framework for UK nurses, midwives and health visitors (Kirk et al. 2003). Seven statements, each with learning outcomes and practice indicators, articulated what were determined to be the minimum standards of knowledge and skills in genetics

required by the profession as a whole. The framework provided the base for work to develop a set of competencies that could be applied across different health professions in Europe (Skirton et al., 2010a). The United States (US) and Japan are the only other countries with genetics/genomics competencies for nursing (Consensus Panel on Genetic/Genomic Nursing Competencies, 2009, Greco et al 2012, Arimori 2007). There are no competence frameworks specifically for midwifery.

It is estimated that in the UK in 2017 there were just over 31,500 practicing midwives, equating to approx. 40 midwives per 1000 live births (Organisation for Economic Co-Operation and Development, 2018). Current midwifery education and training within the UK is based on the pre-registration standards set out by the Nursing and Midwifery Council (NMC, 2009). Education and training programmes are run at approved universities across the country and take a minimum of three years (BSc, BMid or MSc) or 18 months (postgraduate diploma or degree) for those with an adult nursing qualification. There is no detailed curriculum and individual higher education institutions decide how to structure training and assessments in order that their students meet the requirements for practice at the point of registration. As a result there is no specific guidance on the genomics knowledge, skills or attitudes required for competence by students or the practising midwife.

Skirton and colleagues (2012) in their paper on nursing competence discuss the importance of confidence in addition to knowledge and skills and the role it may play in an individual's willingness to use their knowledge and skills. Confidence in undertaking genetic based activities in clinical practice has been shown to be low within the midwifery profession (Metcalfe et al. 2008, Benjamin et al. 2009) although showing some improvement over time



(Crane et al. 2012) however the differences may be a result of education, training and/or healthcare systems between countries. Pre-registration education in genetics in the UK was also found to be patchy and insubstantial when Kirk and Tonkin (2006) surveyed UK nurse and midwifery educators, using the original competency framework as a benchmark. None of the competencies were being achieved in full in any institution for any midwifery programme and under half of the midwifery programmes that responded (n=46) assessed any learning in genetics. A subsequent systematic literature review (Skirton et al., 2010b) determined that midwives in the UK and in Japan were not satisfactorily achieving any of their country's prescribed competencies in genetics at that time. The number of empirical studies that have looked at midwifery confidence, competence and education in genetics/genomics is small and there are no data available to determine whether this picture has changed in recent years. Studies of specific aspects of practice might provide some insights but would have limited value considering the actual breadth of competence required. We suggest that whilst there might be pockets of improvement driven by local/individual interest in genomics and developments in maternal/child services, wide scale, consistent improvement across the midwifery profession is unlikely to have occurred in the absence of focused initiatives.

Aware of the significant advances being made across healthcare in relation to genetics and genomics and the anticipated developments in midwifery practice, the authors made a decision to undertake a review of the Kirk et al., 2003 framework. Additionally, it was decided to consider midwifery independently from nursing, thus allowing the development of specific competency statements by the profession, which could be used to help address gaps in education, training and practice.

This paper sets out the approach taken to produce the framework, the outcome and the implications for the profession across the UK and internationally.

## **Methods**

### ***Consensus panel***

A stakeholder expert panel consensus meeting, broadly based on the established Nominal Group Technique (Delbecq et al. 1975), was selected for data collection having been applied successfully to similar studies by team members for over a decade (Authors 2003, Authors 2013a and b). The method allows for structured interaction within a group through an iterative process of idea generation, feedback, discussion and voting. The conceptual framework for the event and details of the participative thematic analytical approach taken, are set out by Authors (2013). In summary, stakeholders with expertise and experience from a range of backgrounds (midwifery practice, management, education and policy, and genetic counselling) were invited to a one day workshop in June 2010. Travel expenses were reimbursed. Participants were identified through the professional networks of team members and colleagues, or selected based on their role within an organisation or professional body including national antenatal/newborn screening programmes, the Nursing and Midwifery Council, Royal College of Midwives and the Royal College of Nurses (midwifery and women's health). Numbers were limited to ensure that everyone would be able to voice their opinions and contribute to the activities. Those unable to attend were asked to nominate someone with a similar background and area of expertise. Importantly not all participants were known to the team or were familiar with the original framework

prior to the event. With the exception of those working as genetic counsellors, an in depth knowledge of genetics was not a requirement to attend, as the team were looking to engage with individuals and organisations who had realistic and appropriate expectations of the role of the midwife. All participants received a pre-meeting information pack which included the original framework and copies of nine real-life stories which were used as a focus for the meeting (Table 1).

### ***Data collection***

Following an initial presentation providing context for the meeting, participants undertook group work to review a number of personal narratives from women, their families and health professionals illustrating a range of situations including pregnancy, screening, testing and being the parent of someone with a genetic condition. The content of the stories used is summarised in Table 1. Real stories were selected over scenarios in order to reduce the potential for bias. Using the personal narratives available from the Telling Stories Understanding Real Life Genetics website [www.tellingstories.nhs.uk](http://www.tellingstories.nhs.uk) (Kirk et al. 2013), 11 stories relevant to midwifery practice were identified and reviewed by the team with six selected for use during the workshop (Table 1A). Recognising that a number of the stories refer to quite rare conditions that may not be experienced by many midwives during their careers, three additional narratives related to national screening programmes were made available to the groups (Table 1B).

Each of the three groups of six participants comprised a combination of individuals from midwifery practice, education, management/policy and genetic counselling and all were joined by one of the authors to facilitate, but not lead, the work. Each group reviewed four

stories, with each story being reviewed sequentially by two groups. Participants considered two questions: 1) *What are the needs of the woman & her family?* and 2) *What does the midwife need to know, think and do to meet those needs?*, and captured their discussions on a story-specific worksheet. Through the iterative process, responses from other groups were reviewed and additional points added to the worksheets. Responses to the second question were then mapped by participants to the competency statements in the original framework to identify gaps and areas requiring updating. A project team member (*initials*) from outside the fields of midwifery and genetics then facilitated discussion of the potential gaps identified. The discussion was audio recorded and detailed field notes were taken by a team member (*initials*). Electronic voting (Turning Technologies) was used to capture and track opinion, and provide instant feedback to prompt further discussion. Questions and answer options (e.g. yes/no or multiple choice), were incorporated into PowerPoint slides either ahead of the event or in response to discussion on the day. Each person used a handheld wireless keypad to register their selection and responses were immediately displayed by the software in the presentation slide. Participants voted anonymously for the inclusion/exclusion of new themes into the midwifery framework, thus reducing conforming influences of other participants. The cut-off for inclusion of a theme was set at a two-thirds majority (n=12). The majority preference was then taken for the theme to be incorporated into the framework as either a new competency or more explicitly within a current statement.

Looking to the future, participants were asked to identify and consider topics that could have an impact on the framework's validity or utility. For example, new health service initiatives; developments outside the health service (e.g. private healthcare provision) that

would have an impact on midwives; or direct scientific developments that would change practice.

Using the data, audio recording and field notes, the team revised the competencies from the original framework. Following an email consultation with participants, wording for the competencies was finalised and approved. Learning outcomes (LOs) and practice indicators (PIs) were then developed. Where competencies overlapped with the revised nursing framework (Authors, 2013), the corresponding LOs and PIs (developed by a working group of educators) were used as a starting point. Additional content was added by the authors to address the midwifery specific elements and the draft document was subsequently distributed for review and refinement by the midwifery educators that attended the consensus meeting.

### ***Ethical considerations***

Attendance at and contribution to this voluntary meeting was viewed as providing consent to participate. Participants were aware of audio-recording, note-taking and photography and were able to request that their image was not used. The *[organisation funding the review]* was informed at the time by the UK Central Office for Research Ethics Committees that the work did not require NHS ethics approval. The *[organisation]* worked within the governance framework of *[Hospital name]* NHS Foundation Trust.

### **Findings**

Using the audience response system, participants identified their primary role. Of the 17 (of 18) participants present at this point, four described their role as practising midwives, four

as working within management/policy, six as educators and three as genetic counsellors.

When asked “To what extent is good midwifery care currently compromised by midwives’ level of genetic competence?”, 15 (n=17) indicated on a five-point Likert scale (Fig. 1) that it was compromised to some extent; one educator believed that there was no compromise and one (also an educator) ‘did not know’.

### ***Themes, content mapping and identification of gaps***

Participants received all nine stories to read ahead of the meeting. Having each reviewed in-depth four stories at the event, attendees agreed that the six from [www.tellingstories.nhs.uk](http://www.tellingstories.nhs.uk) were wholly appropriate to meet the aims of the workshop and review of the additional stories (Table 1B) was not necessary.

In mapping each of the points identified under *What does the midwife need to know, think and do to meet those needs?* to the existing combined nursing and midwifery framework, groups were consistent in identifying that all of the statements, with the exception of competency 3 in Kay’s story, were present in each of the narratives (Table 2). These data indicated that the statements’ content remained broadly valid. As part of group feedback to all workshop participants, points that did not appear to map to the competencies were identified and deliberated upon. Points were often identified by both groups reviewing a story. Some points were present in multiple stories indicating they were not unique to one situation/story. Synthesis of the discussion by the session facilitator resulted in eight themes which participants agreed were absent or not sufficiently explicit within the current combined framework: *ongoing care, advocacy, multi-professional team working, listening, timeliness, client knowledge, broad knowledge and key indicators (of disease)*. These were discussed and deliberated further by the whole group.

**Ongoing Care:** Participants discussed the importance of the ongoing care provided by the midwife, recognising that the midwife remains the primary person for the women during pregnancy and the first few weeks after birth. It was acknowledged that the midwife should continue to look after women who are referred to specialist (genetics) services and not to assume that all care needs are being met by the genetics specialists. The midwife was viewed as key to providing support during periods of uncertainty, including waiting for invasive procedures and diagnostic tests results, and dealing with inconclusive outcomes.

**Advocacy:** A number of stories were seen to illustrate that often there is no single person taking control of overall care. Although the midwife might be involved in the referral process, they were also viewed as someone who should act as a link-person throughout the pregnancy. They should know what is going on, co-ordinate care or act as the women's advocate and represent the voice of the women in the multi-professional environment to ensure appropriate co-ordination. As an autonomous practitioner, this leadership/co-ordinator role was discussed in terms of the midwife taking on the responsibility to ensure the right level of care was delivered by the right people, using skills that should be present at the point of registration and developed through preceptorship (a structured period of transition for the newly qualified midwife when they start employment in the UK National Health Service) and the early career.

**Multi-professional team working:** Although this theme is not unique to genetic conditions, the majority of participants agreed that the development of this framework was an important opportunity to reiterate and strengthen the need for a multi-professional team approach to the care of women and their families. As care and management for any one genetic condition can often involve many different (health) professionals, the midwife can

be both a sign-poster to care and provide a consistent point of contact for other specialties.

At all times the midwife should be working in partnership with both the multi-disciplinary/professional team and the woman and her family.

**Listening:** As well as providing an opportunity to understand and empathise with a situation, listening effectively was seen as a key skill which can provide an opportunity to determine whether a woman and/or her family would benefit from a genetic referral or further information, even when they might first appear to be knowledgeable about a condition. This was illustrated by one participant who commented:

*How would you pick out that that family may have been in need of a genetic referral?  
You meet families all the time with quite complicated histories but 'how' do you listen to them and think 'yes, I think she needs more information; I need more information' or to refer on?*

Being mindful of the range of biological, psychological and social issues associated with genetic conditions was viewed as something that would enable practitioners to be attentive to cues and triggers for referral.

**Timeliness:** The inappropriate timing of a referral (whether during pregnancy, in the newborn period or in advance of subsequent pregnancies) has the potential to cause significant (psychological) harm to the woman and her family. Whilst it was agreed that timeliness was implicit within the original competence #5 (Supplementary Material Table A), participants discussed the need for more explicit information for midwives that highlights the reality that information giving, decision making and testing are time critical.



In addition to highlighting the importance of timely action, the themes of multidisciplinary working and advocacy are also reflected in the following quote:

*With genetics and pregnancy, everything to do with pregnancy isn't something that can be left for a certain period of time, you have time frames to work within. If this women is wanting pre-natal diagnosis for example, you can't be leaving that until the next available appointment, it's got to be done within a certain timeframe. Which means that in order to offer that service you've got to be getting information from all these different disciplines and who is going to co-ordinate all that if the midwife isn't acting as the advocate?*

**Client knowledge:** From some of the stories it was also clear to participants that families can be experts in their condition. Acknowledging client knowledge and treating individuals as experts was recognised as being important and linked with the need to work in partnership with them, ensuring that information and services are appropriately tailored. The discussion emphasised that it was equally important not to make assumptions about client understanding or prior experience.

**Broad knowledge:** Discussions around the scope of knowledge required by midwives centred on whether practitioners need a broad knowledge of genetics and genomics, or an in-depth knowledge of specific conditions. An expectation for midwives to know about many rare conditions was viewed as unnecessary and a potential deterrent to them embracing genomics. Participants were comfortable with the point made that there should be an expectation that all midwives should have an understanding of core principles (e.g. patterns of inheritance), that they could apply appropriately to the range of clinical situations that they might encounter and that could be built upon as services developed. However, for midwives involved in offering antenatal and new born screening for example,

participants expected a greater knowledge of each condition in order that fully informed consent/decision to decline could be ensured. Where gaps in clinical knowledge are identified, individuals should know where and how to get credible information including contacting their regional genetics centre.

**Key indicators of disease:** Participants recognised that some individuals under the care of a midwife may not have a diagnosis or an awareness of a possible family history but would benefit from specialist input. In appreciating other factors that may be present including key indicators of genetic conditions such as unusual facial or physical features, clinical symptoms and multiple miscarriages, the midwife would be in a position to recognise potential indicators and facilitate timely referral.

Following in-depth discussion and anonymous voting (Table 3) all eight themes were selected for inclusion within existing statements.

### ***Impact of future developments in science and practice***

In considering potential challenges to the validity or utility of the new framework, participants identified and discussed three issues related to the health service generally: 1) a shortfall in the number of midwives that could potentially lead to other roles providing screening information/services; 2) the potential for variability of service provision across the country, for example due to local decisions or funding; and 3) private indemnity insurance. In terms of technological advancement, direct to consumer testing (e.g. for cystic fibrosis carrier status); whole genome sequencing and the associated issues around the interpretation and disclosure of findings; pharmacogenomics and non-invasive prenatal screening/testing were discussed. None of the topics were deemed to warrant an additional

competency or specific mention, but it was suggested that the technological changes would make some competencies even more relevant to midwifery practice.

### ***The new framework***

Approved by participants, key additions in the new genetics/genomics competency framework for midwives (Table 4) not present in the combined nursing professions framework (Supplementary Material Table A) include: the need to incorporate family history information as part of a comprehensive midwifery assessment and the ability to recognise key indicators of a genetic condition within *Statement 1*. The time-critical nature of information giving, decision making, testing and referral has also been emphasised in *Statement 1* and again in 5. Changing needs throughout the period of midwifery care and the role of the midwife during periods of uncertainty are highlighted in *Statement 3*. *Statement 6* focuses on the responsibility of midwives to keep up to date with genomics as it applies to their area of practice as part of continuing professional development as well as on a case-by-case basis, and *Statement 7* emphasises the skills of critical appraisal in selecting information and the importance of utilising a range of sources including the expert patient.

Taking the approach of Skirton and colleagues (2006), suggested learning outcomes have been aligned to levels 4, 5 and 6 of the QAA framework (The Quality Assurance Agency for Higher Education 2008) corresponding to years 1, 2 and 3 respectively of direct-entry pre-registration undergraduate training. Learning outcomes and practice indicators were subsequently reviewed for clarity, appropriateness and omissions by the midwifery educators who had been at the meeting and no amendments were required.

(Supplementary Material Table B).

## Discussion

To the best of our knowledge, this study presents the first competence-based education framework that defines the knowledge and skills in genetics/genomics required specifically by midwives. In the equivalent nursing focused review (Authors, 2013), participants identified three over-arching themes *Advocacy*, *Ongoing care* and *Information management* that were believed to be inadequately addressed within the original framework and merited further discussion. With eight themes identified in this study and a clear midwifery focus to the final framework we believe the decision to consider midwifery independently from nursing was justified.

In proposing a set of learning outcomes and practice indicators (Supplementary Table B) that sit beneath each of the seven competency statements (Table 4), the authors hope to provide a useful tool for educators considering where and how to fit genetics/genomics into their curricula, and for trainers and managers who may be looking to improve the delivery of genetics/genomics aspects of midwifery practice. In providing outcomes that change over time, educators and trainers are offered a means to develop and assess student/trainee knowledge and skills at multiple points and as experience increases. Educators delivering midwifery training in other countries or shortened courses in the UK for qualified registered nurses, can select the most appropriate LO for any given time-point in their course. The end-user should not view the order of the competencies as a hierarchy with, for example #1 being more important than the others. Equally the competencies should not be viewed in isolation as each one is underpinned by the knowledge, skills and attitudes set out in the rest.

We plan to test the utility of the framework in helping inform and shape pre-registration midwifery education in the UK as the new NMC standards for midwifery education (NMC, 2018) are implemented. Studies are also required to understand the best approaches to achieving high quality genomics education for midwives pre- and post-registration and methods of accurately assessing genomic competence and confidence. Having access to relevant and accurate resources is an important factor (Tonkin et al., 2011) and effort is needed to develop and collate these. Initiatives like those of Health Education England's Genomics Education Programme ([www.genomicseducation.hee.nhs.uk](http://www.genomicseducation.hee.nhs.uk)) are important in engaging with midwives.

Whilst on initial inspection a national consensus meeting involving just 18 participants may appear under-powered, it is important to remember that rather than starting from scratch, this event built on previous work produced by more than 40 stakeholders. Involvement of the other health or social-care professions who work with midwives to provide care might have enriched discussions but could have also resulted in loss of focus and risked losing any feelings of ownership by midwives for the competencies if they felt they were being told how to train and practice by others. The group, along with the project team, was sufficiently diverse to ensure a broad range of expertise and perspectives, and our priority was to remain focussed on midwifery practice and promote ownership of the competencies developed.

The approach taken allowed the team to both confirm that the original framework was still relevant, and then repurpose it specifically for midwifery practice. Thematic analysis of stories prior to considering the validity of the original combined competencies ensured that

participants were not distracted by the original framework. In addition, the use of personal narratives ensured that the competency content was borne out of real-life experience and is not a result of scenarios written by the team to engineer a specific end goal.

Equally important to the rigour of this approach was the involvement of individuals who did not have a specific interest in genetics/genomics. As a result the authors believe that these individuals brought a balance to both the discussion and the output that could have become one-sided or narrow in focus if only genetic-specialists had been involved. Indeed, the team were challenged during the meeting by participants who questioned the need for such a framework when the content was a reflection of national standards. We believe that this perceived duplication is in fact a strength of the competencies. This framework does not require midwives to practise outside of the Nursing and Midwifery Council standards (NMC, 2015) but rather provides a means for individuals and organisations to consider midwifery practice through a 'genetic lens'. As such, the framework is both relevant to the midwifery role and realistic. To illustrate this, examples are given in Table 5 of where each competence would already be applied in practice today. We believe that these competencies would be transferable for use in other countries around the world and could be repurposed for similar roles involved in pre- and post-natal care.

On-going utility of this framework is crucial. The framework sets out principles for practice. By not including details of specific conditions or tests, these competencies can accommodate changes to midwifery services as it has already done over the intervening period since the workshop was held and the competencies written. The framework would not require updating when, for example, additional conditions are added to screening tests or technologies like NIPT and WGS/WES supersede current methods. Genomics within

healthcare and associated areas such as pharmacogenomics and epigenomics are rapidly moving fields and as such this framework is more relevant now than ever. Future applications within midwifery are likely to include genome analysis to inform risk prediction for pregnancy related conditions as well as drug choice and dosage (pharmacogenomics). As science continues to understand more about how lifestyle and environment can lead to heritable and reversible chemical modifications of the genome that can alter gene function (epigenomics), the role of the midwife and other health professionals in promoting positive lifestyle behaviours to improve the health of mother, child and future generations may become increasingly important. Genomics also offers up many ethical challenges to society. Genome editing technology offers the potential to remove disease causing errors from an individual's DNA. Midwives should actively contribute to the ethical debates around future clinical applications of genome editing and the other advances mentioned here. This framework can provide midwives with the core competencies needed to do this effectively.

## Conflict of Interest

The authors have no financial or personal relationships with other people or organizations that could inappropriately influence (bias) this work.

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**All figures, tables and e-supplementary information provided as separate files**

**Figure 1.** Number of participants responding to the question “To what extent is good midwifery care currently compromised by midwives’ level of genetic competence?” (n=17)  
[Five point Likert scale with an additional ‘don’t know’ option]

**Table 1.** Personal narratives used within A) the group work and B) provided in the pre-meeting reading pack but not used at the meeting

**Table 2.** Original genetics framework competency statements<sup>1</sup> present in each of the stories (listed by storyteller name). Short descriptive headings (numbered 1-7) are provided in place of the full statement.

**Table 3.** Results of anonymous voting (n=18) for the incorporation into, or exclusion from, the new midwifery genetics/genomics framework of eight themes identified through group review of personal narratives.

**Table 4.** Midwifery competencies in genetics/genomics

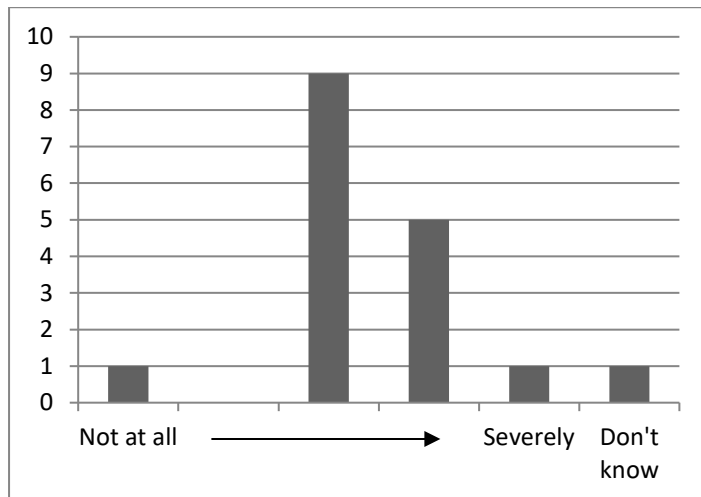
**Table 5.** Midwifery competencies in genetics/genomics (‘headline’ sentence only) and example of midwifery practice that illustrate each statement.

**e-Component: Supplementary Material**

**Table A.** Original genetics competency statements for UK nurses, midwives and health-visitors (Kirk et al.2003)

**Table B** Learning Outcomes and Practice Indicators for midwifery competences in genetics/genomics

**Figure 1.** Number of participants responding to the question “To what extent is good midwifery care currently compromised by midwives’ level of genetic competence?” (n=17)  
[Five point Likert scale with an additional ‘don’t know’ option]



**Table 1.** Personal narratives used within A) the group work and B) provided in the pre-meeting reading pack but not used at the meeting

A

Storyteller	Perspective	Overview	Origin <sup>1</sup>
<b>Ann</b>	Health professional	Working with families affected by muscular dystrophy.	<a href="http://www.tellingstories.nhs.uk/stories.asp?id=14">http://www.tellingstories.nhs.uk/stories.asp?id=14</a>
<b>Rachel</b>	Mother	Rachel's two children have cystic fibrosis.	<a href="http://www.tellingstories.nhs.uk/stories.asp?id=20">http://www.tellingstories.nhs.uk/stories.asp?id=20</a>
<b>Rhiannon</b>	Daughter had spinal muscular atrophy with respiratory distress (SMARD)	Receiving a diagnosis (Spinal Muscular Atrophy with Respiratory Distress) through to prenatal testing.	<a href="http://www.tellingstories.nhs.uk/stories.asp?id=49">http://www.tellingstories.nhs.uk/stories.asp?id=49</a>
<b>Kay</b>	Mother	Her role as her daughter's advocate. (Costello syndrome)	<a href="http://www.tellingstories.nhs.uk/stories.asp?id=63">http://www.tellingstories.nhs.uk/stories.asp?id=63</a>
<b>Meriel</b>	Mother	Meriel's daughter has Down syndrome.	<a href="http://www.tellingstories.nhs.uk/stories.asp?id=37">http://www.tellingstories.nhs.uk/stories.asp?id=37</a>
<b>Christine</b>	Mother and midwife	Perspectives on Charcot-Marie-Tooth disease.	<a href="http://www.tellingstories.nhs.uk/stories.asp?id=1">http://www.tellingstories.nhs.uk/stories.asp?id=1</a>

<sup>1</sup> [www.tellingstories.nhs.uk](http://www.tellingstories.nhs.uk) is a free-to-access education resource for health professionals

B

Storyteller	Perspective	Overview	Origin
<b>Screening for sickle cell and beta thalassaemia interview 2</b>	Client	Her experiences around screening in pregnancy and how she felt on discovering that she was a beta thalassaemia carrier when she was not aware that she had been tested.	<a href="http://www.healthtalkonline.org">www.healthtalkonline.org</a> <sup>2</sup>
<b>Antenatal screening interview AN19</b>	Client	Her normal first pregnancy and her experiences of routine screening experiences including combined nuchal scan and blood test.	<a href="http://www.healthtalkonline.org">www.healthtalkonline.org</a>
<b>Focus group transcript</b>	Welsh Midwife	An experience of an adverse newborn screening result for Duchenne muscular dystrophy (DMD) <sup>3</sup>	McGregor S 2005

<sup>2</sup> [www.healthtalkonline.org](http://www.healthtalkonline.org) is a free to access resource of personal health experiences

<sup>3</sup> Screening for Duchenne muscular dystrophy was subsequently removed from the Welsh newborn programme in November 2011



**Table 2.** Original genetics framework competency statements<sup>1</sup> present in each of the stories (listed by storyteller name). Short descriptive headings (numbered 1-7) are provided in place of the full statement.

	<i>1 Identify clients who might benefit from genetic services</i>	<i>2 Appreciate sensitivity in tailoring genetic information</i>	<i>3 Uphold rights of clients (in relation to genetics issues)</i>	<i>4 Genetics knowledge to underpin practice</i>	<i>5 Utility &amp; limitations of genetic testing</i>	<i>6 Limitations of own genetics expertise</i>	<i>7 Obtain &amp; communicate information about genetics</i>
<b>Ann</b>	✓	✓	✓	✓	✓	✓	✓
<b>Rachel</b>	✓	✓	✓	✓	✓	✓	✓
<b>Rhiannon</b>	✓	✓	✓	✓	✓	✓	✓
<b>Kay</b>	✓	✓	X	✓	✓	✓	✓
<b>Meriel</b>	✓	✓	✓	✓	✓	✓	✓
<b>Christine</b>	✓	✓	✓	✓	✓	✓	✓

<sup>1</sup> Kirk et al., 2003 and online supplementary material Table A

**Table 3.** Results of anonymous voting (n=18) for the incorporation into, or exclusion from, the new midwifery genetics/genomics framework of eight themes identified through group review of personal narratives.

Voting options:	Themes not present in the original framework:							
	ongoing-care	advocacy	multi-professional team working	listening	timeliness	client knowledge	broad knowledge	key indicators (of disease)
This merits an additional competency	5 (28%)	3 (17%)	4 (22%)	0	3 (17%)	0	2 (11%)	0
This should be made more explicit within a current competency statement	9 (50%)	9 (50%)	8 (44%)	13 (72%)	12 (67%)	14 (78%)	11 (61%)	14 (78 %)
No, this should not be included in the framework	3 (17%)	5 (28%)	5 (28%)	5 (28%)	2 (11%)	4 (22%)	5 (28%)	3 (17%)
Unsure	1 ( 6%)	1 ( 6%)	1 ( 6%)	0	1 ( 6%)	0	0	1 ( 6%)

**Table 4. Midwifery competencies in genetics/genomics**

<p><b>1. Identify individuals who might benefit from genetic services and/or information through a comprehensive midwifery assessment:</b></p> <ul style="list-style-type: none"> <li>• that recognises the importance of family history in assessing predisposition to disease,</li> <li>• recognising the key indicators of a potential genetic condition,</li> <li>• taking appropriate and timely action to seek assistance from and refer individuals to genetics specialists, other specialists and peer support resources,</li> <li>• based on an understanding of the care pathways that incorporate genetics services and information, and by</li> <li>• providing continuity of care and being proactive in co-ordinating care within the multidisciplinary team as appropriate.</li> </ul>
<p><b>2. Demonstrate the importance of sensitivity in tailoring genetic/genomic information and services to the individual's culture, knowledge, language ability and developmental stage:</b></p> <ul style="list-style-type: none"> <li>• listening to and acknowledging an individual's prior experience,</li> <li>• recognising that ethnicity, culture, religion, ethical perspectives and developmental stage may influence the individual's ability to utilise information and services,</li> <li>• demonstrating the use of appropriate communication skills in relation to the individual's level of understanding of genetic/genomic issues.</li> </ul>
<p><b>3. Advocate for the rights of all individuals to informed decision making and voluntary action:</b></p> <ul style="list-style-type: none"> <li>• based on an awareness of the potential for misuse of human genetic/genomic information,</li> <li>• understanding the importance of delivering genetic/genomic information and counselling accurately and without coercion or personal bias,</li> <li>• being responsive to changing needs throughout the period of care,</li> <li>• providing support during periods of uncertainty,</li> <li>• recognising that choices and actions may differ with each pregnancy, and</li> <li>• recognising that personal values beliefs of self and individuals may influence the care and support provided during decision-making.</li> </ul>
<p><b>4. Demonstrate a knowledge and understanding of the role of genetic/genomic and other factors in maintaining health and in the manifestation, modification and prevention of disease expression, to underpin effective practice:</b></p> <ul style="list-style-type: none"> <li>• which include core genetic/genomic concepts that form a sufficient knowledge base for understanding the implications of specific conditions that may be encountered.</li> </ul>
<p><b>5. Apply knowledge and understanding of the utility and limitations of genetic/genomic information and testing to underpin care and support for women and families prior to, during and following decision-making, that:</b></p> <ul style="list-style-type: none"> <li>• incorporates awareness of the ethical, legal and social issues related to testing, recording, sharing and storage of genetic/genomic information,</li> <li>• incorporates awareness of the potential physical, emotional, psychological and social consequences of genetic/genomic information for individuals, family members, and communities, and</li> <li>• recognises that decision-making and testing during pregnancy is usually time-critical.</li> </ul>
<p><b>6. Examine one's own competence of practice on a regular basis:</b></p> <ul style="list-style-type: none"> <li>• recognising areas where professional development related to genetics/genomics would be beneficial,</li> <li>• maintaining awareness of clinical developments in genetics/genomics that are likely to be of most relevance to maternal and family health, seeking further information on a case-by-case basis,</li> <li>• based on an understanding of the boundaries of one's professional role in the referral, provision or follow-up to genetics services.</li> </ul>
<p><b>7. Obtain and communicate credible, current information about genetics/genomics, for self, women, families and colleagues:</b></p> <ul style="list-style-type: none"> <li>• using information technologies and other information sources effectively to do so,</li> <li>• applying critical appraisal skills to assess the quality of information accessed,</li> <li>• listening to and working in partnership with family members and other agencies in the management of conditions, and</li> <li>• recognising the potential expertise of individuals, family members and carers with genetic/genomic healthcare needs that develops over time and with experience.</li> </ul>

**Table 5.** Midwifery competencies in genetics/genomics ('headline' sentence only) and example of midwifery practice that illustrate each statement.

<b>1. Identify individuals who might benefit from genetic services and/or information through a comprehensive midwifery assessment</b>	Taking and drawing a family history ('pedigree' / 'family tree') to capture information provided by a women at her first appointment. She is concerned about her pregnancy as her nephew has recently been diagnosed with a 'muscle condition'. Discussing the information gathered with colleagues and referring on according to local guidelines.
<b>2. Demonstrate the importance of sensitivity in tailoring genetic/genomic information and services to the individual's culture, knowledge, language ability and developmental stage</b>	Discussion of a positive newborn screening result with a family whose first language isn't English. Ensuring that someone is present to translate and that questions are asked in a way that answers will confirm the family have understood the information that they have been given.
<b>3. Advocate for the rights of all individuals to informed decision making and voluntary action</b>	Providing care for a couple who have become pregnant through the process of IVF and pre-implantation genetic diagnosis (PGD). Recognising that decisions around this pregnancy are informed by their prior experience of a life limiting condition (loss of one child very soon after birth and the decision to terminate two subsequent affected pregnancies following prenatal testing).
<b>4. Demonstrate a knowledge and understanding of the role of genetic/genomic and other factors in maintaining health and in the manifestation, modification and prevention of disease expression, to underpin effective practice</b>	Understanding why providing guidance on folic acid supplementation and limiting foods rich in vitamin A is important.
<b>5. Apply knowledge and understanding of the utility and limitations of genetic/genomic information and testing to underpin care and support for women and families prior to, during and following decision-making</b>	Supporting a women and her family as they make a decision to have or decline an invasive diagnostic test (amniocentesis or chorionic villus sampling) following a high-risk antenatal screening result. Understanding the limits of the information that the test can provide and that the procedure carries a risk of miscarriage.
<b>6. Examine one's own competence of practice on a regular basis</b>	Attending continuing professional development sessions or use of online training resources to remain up-to-date in practice as new conditions are added to the newborn screening test list or new-technologies supersede current practice (e.g. NIPT replacing combined screening)
<b>7. Obtain and communicate credible, current information about genetics/genomics, for self, women, families and colleagues</b>	Finding out more about a pre-existing genetic condition that has implications for a mother's health during pregnancy and delivery. Working with the women to agree a care plan.

## e-Supplementary File

**Table A.** Original genetics competency statements for UK nurses, midwives and health-visitors (Kirk et al.2003)

<p><b>1. Identify clients who might benefit from genetic services and information:</b></p> <ul style="list-style-type: none"> <li>• through an understanding of the importance of family history in assessing predisposition to disease,</li> <li>• seeking assistance from and referring to appropriate genetics experts and peer support resources, and</li> <li>• based on an understanding of the components of the current genetic counselling process.</li> </ul>
<p><b>2. Appreciate the importance of sensitivity in tailoring genetic information and services to clients' culture, knowledge and language level:</b></p> <ul style="list-style-type: none"> <li>• recognising that ethnicity, culture, religion and ethical perspectives may influence the clients' ability to utilise these.</li> </ul>
<p><b>3. Uphold the rights of all clients to informed decision making and voluntary action:</b></p> <ul style="list-style-type: none"> <li>• based on an awareness of the history of misuse of human genetic information and</li> <li>• understanding of the importance of delivering genetic education and counselling fairly, accurately and without coercion or personal bias,</li> <li>• recognising that personal values and beliefs may influence the care and support provided to clients during decision-making.</li> </ul>
<p><b>4. Demonstrate a knowledge and understanding of the role of genetic and other factors in maintaining health and in the manifestation, modification and prevention of disease expression, to underpin effective practice.</b></p>
<p><b>5. Demonstrate a knowledge and understanding of the utility and limitations of genetic testing and information:</b></p> <ul style="list-style-type: none"> <li>• including the ethical, legal and social issues related to testing and recording of genetic information and</li> <li>• the potential physical and/or psychosocial consequences of genetic information for individuals, family members, and communities.</li> </ul>
<p><b>6. Recognise the limitations of one's own genetics expertise:</b></p> <ul style="list-style-type: none"> <li>• based on an understanding of one's professional role in the referral, provision or follow-up to genetics services.</li> </ul>
<p><b>7. Obtain and communicate credible, current information about genetics, for self, clients and colleagues</b></p> <ul style="list-style-type: none"> <li>• using information technologies effectively to do so.</li> </ul>

## Learning Outcomes and Practice Indicators for Midwifery Competencies in Genetics/Genomics

<p>Competency 1</p> <p><b>Identify individuals who might benefit from genetic services and/or information through a comprehensive midwifery assessment:</b></p> <ul style="list-style-type: none"> <li>that recognises the importance of family history in assessing predisposition to disease,</li> <li>recognising the key indicators of a potential genetic condition,</li> <li>taking appropriate and timely action to seek assistance from and refer to genetics specialists and peer support resources,</li> <li>based on an understanding of the care pathways that incorporate genetics services and information, and by</li> <li>providing continuity of care and being proactive in co-ordinating care within the multidisciplinary team as appropriate.</li> </ul>			
Level 4 Learning Outcomes (Year 1)	Level 5 Learning Outcomes (Year 2)	Level 6 Learning Outcomes (Year 3)	Practice Indicators
1.1.1 Outline the relevance of a multi-generational family history in relation to assessing genetic health risk.	1.2.1 Acquire and record accurate information for the construction of a multi-generational family history to assess genetic health risk.	1.3.1 Construct a multi-generational family history for the process of assessing genetic health risk.	Demonstrate the ability to collect information as part of a comprehensive midwifery assessment and use the information to draw a family history using standard symbols.
1.1.2 Describe the key indicators of a genetic condition.	1.2.2 Explore significant family history and other key indicators to recognise an increased risk of a genetic condition.	1.3.2 Interpret significant family history and other key indicators to assess a potential risk of a genetic condition.	Recognise and document potentially significant genetic/genomic information from a comprehensive midwifery assessment and family health history.
1.1.3 Describe basic patterns of biological inheritance and their variation in families and populations.	1.2.3 Distinguish patterns of biological inheritance and their variation in families and populations.	1.3.3 Differentiate patterns of biological inheritance & explain how these may vary in families and populations.	
1.1.4 List resources available for professionals seeking genetic information.	1.2.4 Evaluate relevant genetic information resources to inform practice.	1.3.4 Utilise relevant genetic resources and peer support/expertise of colleagues to inform practice.	Apply knowledge of local and regional referral pathways to explain to patients the services that are available.
1.1.5 Identify the different types of services and other agencies which can support individuals and families with or at risk of a genetic condition.	1.2.5 Describe the roles of specialist genetic practitioners and the range of services they provide.	1.3.5 Appraise the role of specialist genetic services and other agencies in the provision of appropriate patient/client care.	Facilitate timely referral to genetic services and other agencies when appropriate.
1.1.6 Outline the importance of timely and appropriate referral to genetic services.	1.2.6 Explore the implications for individuals and families of failing to refer to genetic services.	1.3.6 Describe a typical care pathway which incorporates genetic services and information.	Contribute to the co-ordination of an individual's care, providing continuity and demonstrating leadership as appropriate.

<p>Competency 2</p> <p><b>Demonstrate the importance of sensitivity in tailoring genetic/genomic information and services to the individual's culture, knowledge, language ability and developmental stage:</b></p> <ul style="list-style-type: none"> <li>• listening to and acknowledging an individual's prior experience,</li> <li>• recognising that ethnicity, culture, religion, ethical perspectives and developmental stage may influence the individual's ability to utilise information and services,</li> <li>• demonstrating the use of appropriate communication skills in relation to the individual's level of understanding of genetic/genomic issues.</li> </ul>			
Level 4 Learning Outcomes (Year 1)	Level 5 Learning Outcomes (Year 2)	Level 6 Learning Outcomes (Year 3)	Practice Indicators
<p>2.1.1 Outline how ethnicity, culture, religion and ethical perspectives of women and their families may influence their understanding and use of genetic/genomic information and services.</p> <p>2.1.2 Recognise how communication of genetics issues should take into account a woman's level of understanding.</p> <p>2.1.3 Recognise that women or their family may have prior experience of a genetic condition.</p>	<p>2.2.1 Discuss the impact of ethnicity, culture, religion and, ethical perspectives on a woman's potential use of genetic/genomic information and services.</p> <p>2.2.2 Demonstrate the use of appropriate communication skills in relation to a woman's level of understanding of genetic/genomics issues.</p> <p>2.2.3 Describe ways in which prior experience may impact a person's requirements for genetic/genomic information and services.</p>	<p>2.3.1 Critically evaluate the significance of ethnicity, culture, religion and ethical perspectives on a woman's potential use of genetic/genomic information and services.</p> <p>2.3.2 Effectively communicate genetic/genomic issues at a women's level of understanding.</p> <p>2.3.3 Explore issues that may impact on requirements for genetics/genomics information with clients in a sensitive manner</p>	<p>Demonstrate the ability to work sensitively with women to elucidate their ethnic, cultural, religious and ethical perspectives.</p> <p>Demonstrate effective communication of genetic/genomic issues having identified and assessed the woman's understanding of genetic/genomic information.</p> <p>Tailor genetic/genomic information to meet individual needs taking into account the cultural, ethnic, religious and ethical perspectives as well as developmental stage and prior experience, and using resources to facilitate effective communication as appropriate.</p>

### Competency 3

#### **Advocate for the rights of all individuals to informed decision making and voluntary action:**

- based on an awareness of the potential for misuse of human genetic/genomic information,
- understanding the importance of delivering genetic/genomic information and counselling accurately and without coercion or personal bias,
- being responsive to changing needs throughout the period of care,
- providing support during periods of uncertainty,
- recognising that choices and actions may differ with each pregnancy, and
- recognising that personal values, beliefs of self and client may influence the care and support provided during decision-making.

<b>Level 4 Learning Outcomes (Year 1)</b>	<b>Level 5 Learning Outcomes (Year 2)</b>	<b>Level 6 Learning Outcomes (Year 3)</b>	<b>Practice Indicators</b>
3.1.1 Explain how one's own beliefs and values can influence client care.	3.2.1 Explore how personal values and beliefs in relation to ethical, cultural, religious and ethnic issues could impact on client care.	3.3.1 Critically evaluate the significance of personal values and beliefs in relation to ethical, cultural, religious and ethnic issues in the context of client care.	Articulate situations where people's values and beliefs might impact on care, and work reflectively to minimise negative impact of individual practitioner values and beliefs on care provision.
3.1.2 Identify past and potential future misuse of genetic/genomic information.	3.2.2 Discuss how the misuse of genetic/genomic information could potentially influence a woman's ability to make an informed decision and act voluntarily.	3.3.2 Appraise the impact of genetic/genomic information misuse on a woman's ability to make an informed decision and take voluntary action.	Identify situations where women may be vulnerable to coercion and involuntary action.
3.1.3 Recognise the rights of all women to informed decision making and voluntary action.	3.2.3 Facilitate women's rights to self determination through ensuring informed decision making and voluntary action.	3.3.3 Uphold women's rights to self determination through ensuring informed decision making and voluntary action.	Assess a woman's ability to make informed decisions and trigger best interest process.
		3.3.4 Recognise situations where autonomous choice may have an adverse impact on the health of the individual, or others may be adversely affected.	Ensure women are aware of the potential adverse effects of their decisions on their own health or that of other family members.
	3.2.4 Ensure that the particular needs of those unable to give informed consent in relation to accessing genetic/genomic information are addressed.	3.3.5 Advocate the particular needs of those unable to give informed consent in relation to accessing genetic/genomic information.	Work with colleagues, the woman and their family to prevent/limit harm or adverse health impact to your client or other family member(s).
			Where or when appropriate, act as an advocate or work with advocacy agencies.



3.1.4 Describe the key points in the preconception, pregnancy and postnatal periods of care where a genetic condition may be identified.	<p>3.2.5 Explain how a diagnosis or potential diagnosis of a genetic condition (in mother or child) may impact the woman/family during the period of care.</p> <p>3.2.6 Consider the effects that uncertainty over a situation may have on information and care needs, decision making and family dynamics.</p> <p>3.2.7 Explore how choices and actions may differ between each pregnancy.</p>	<p>3.3.6 Analyse how the principle of a non-directive approach underpins the process of genetic counselling, in facilitating client autonomy and empowerment.</p> <p>3.3.7 Apply knowledge and understanding of the impact of genetic conditions to plan care and anticipate needs.</p> <p>3.3.8 Develop approaches to providing appropriate and responsive support.</p>	Demonstrate knowledge and understanding of genetics and genomics appropriate to preconception, pregnancy and postnatal periods of care, when carrying out a midwifery assessment and delivering care.
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#### Competency 4

**Demonstrate a knowledge and understanding of the role of genetic/genomic and other factors in maintaining health and in the manifestation, modification and prevention of disease expression, to underpin effective practice:**

- which include core genetic/genomic concepts that form a sufficient knowledge base for understanding the implications of specific conditions that may be encountered

Level 4 Learning Outcomes (Year 1)	Level 5 Learning Outcomes (Year 2)	Level 6 Learning Outcomes (Year 3)	Practice Indicators
<p>4.1.1 Discuss how genetic and genomic factors affect health and disease.</p> <p>4.1.2 Outline how disease expression throughout the life-cycle is affected by both genetic and genomic factors.</p>	<p>4.2.1 Explore the role of genetic and genomic factors in altered health states using examples of common inherited conditions and common-complex conditions.</p> <p>4.2.2 Explain with examples, how disease expression throughout the life-cycle may be influenced by genetic and genomic factors.</p>	<p>4.3.1 Apply knowledge of genetic and genomic factors within the human health-disease continuum, including in the context of public health.</p> <p>4.3.2 Critically analyse the impact of genotype and environment throughout the human life-cycle.</p> <p>4.3.3 Appreciate the role of epigenetic markers to aid understanding of <i>in-utero</i> and intergenerational influences on disease predisposition.</p> <p>4.3.4 Distinguish between genetic susceptibility and clinical manifestation of disease</p>	<p>Explain the genetic component contributing to the manifestation of disorders within their sphere of practice.</p> <p>Provide appropriate lifestyle advice based on knowledge of gene-environment interactions.</p> <p>Demonstrate ability to distinguish between individuals at high, medium and low risk of genetic/genomic conditions within their sphere of practice.</p>

		using basic concepts of risk.	
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#### Competency 5

**Apply knowledge and understanding of the utility and limitations of genetic/genomic information and testing to underpin care and support for women and families prior to, during and following decision-making, that:**

- incorporates awareness of the ethical, legal and social issues related to testing, recording, sharing and storage of genetic information,
- incorporates awareness of the potential physical, emotional, psychological and social consequences of genetic information for individuals, family members, and communities, and
- recognises that decision-making and testing during pregnancy is usually time-critical.

Level 4 Learning Outcomes (Year 1)	Level 5 Learning Outcomes (Year 2)	Level 6 Learning Outcomes (Year 3)	Practice Indicators
5.1.1 Explain the need for and maintain privacy and confidentiality when discussing, recording and storing genetic/genomic information.	5.2.1 Demonstrate confidentiality and maintain privacy when discussing, recording and storing genetic/genomic information.	5.3.1 Ensure confidentiality and privacy when discussing, recording and storing genetic information.	Ensure genetic/genomic information is discussed in an appropriate environment.  Obtain consent to share information with other professionals and with other family members as appropriate.
5.1.2 Describe the difference between screening and diagnostic tests and demonstrate awareness of the processes of genetic/genomic screening and testing and their limitations.	5.2.2 Explore potential risks, benefits and limitations of screening and testing and access to genetic/genomic information.	5.3.2 Evaluate potential risks, benefits and limitations of screening and testing and access to genetic information.	Demonstrate awareness of the potential psychological effects of accepting or declining screening and/or testing on the individual and family.
5.1.3 Identify the time-points for screening and testing during pregnancy and the postnatal period.	5.2.3 Discuss the factors that impact access to screening and testing.  5.2.4 Debate the psychological, ethical, legal and social implications of genetic/genomic information for women and families.	5.3.4 Critically appraise the psychological, ethical, legal and social implications of genetic testing and information for women and families.  5.3.4 Integrate understanding of inheritance risk with knowledge of potential bio-psychosocial consequences of genetic/genomic information, to outline potential impact on family dynamics.  5.3.5 Respond appropriately and effectively to enquiries about genetic/genomic concerns recognising the limitations of one's own knowledge.	Work pro-actively to ensure timely referral and to maximise opportunities for information sharing and informed decision making.  Evaluate the appropriateness of genetic genetic/genomic information for women and families.  Incorporate knowledge of inheritance risk and impact on family dynamics to anticipate potential issues when planning care.  Communicate information in an appropriate and sensitive way, involving appropriate health

		5.3.6 Recognise women and families who have needs for ongoing support in relation to genetic conditions	professional(s) as necessary.  Provide or facilitate ongoing support to women and families as appropriate.
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#### Competency 6

##### Examine one's own competence of practice on a regular basis:

- recognising areas where professional development related to genetics/genomics would be beneficial,
- maintaining awareness of clinical developments in genetics/genomics that are likely to be of most relevance to maternal and family health, seeking information on a case-by-case basis,
- based on an understanding of the boundaries of one's professional role in the referral, provision or follow-up to genetics services.

Level 4 Learning Outcomes (Year 1)	Level 5 Learning Outcomes (Year 2)	Level 6 Learning Outcomes (Year 3)	Practice Indicators
6.1.1 Recognise the opportunities for learning related to genetics/genomics knowledge and practice.  6.1.2 Recognise the limitations of your role in the referral, provision or follow-up to genetic services.	6.2.1 Utilise learning resources to improve genetic/genomic knowledge and practice.  6.2.2 Develop a collaborative approach to maternal and family care in relation to genetics, within a multidisciplinary team including other statutory and voluntary organisations.	6.3.1 Maintain contemporaneous knowledge of genetic/genomic developments and the implications for your practice.  6.3.2 Promote a collaborative approach to enhance maternal and family care in relation to genetic/genomic with other statutory and voluntary organisations.	Demonstrate ongoing professional development in genetics/genomics within portfolio.  Demonstrate an awareness of the responsibilities and boundaries of self and others involved in the provision of genetic/genomic care.  Enhance care of the women and child through working collaboratively with other service providers.

## Competency 7

### Obtain and communicate credible, current information about genetics/genomics, for self, women, families and colleagues:

- using information technologies and other information sources effectively to do so,
- applying critical appraisal skills to assess the quality of information accessed,
- listening to and working in partnership with family members and other agencies in the management of conditions, and
- recognising the potential expertise of individuals, family members and carers with genetic/genomic healthcare need that develops over time and with experience.

Level 4 Outcomes (Year 1)	Level 5 Outcomes (Year 2)	Level 6 Outcomes (Year 3)	Practice Indicators
7.1.1 Display an ability to use information technology to retrieve relevant and reliable genetic/genomic information.	7.2.1 Evaluate a range of current genetic/genomic information from reputable sources and assess appropriateness for different practice situations.	7.3.1 Integrate current and credible genetic/genomic information into practice to inform care provision.	Demonstrate ability to select, evaluate and utilise reliable genetic/genomic information that is appropriate to the situation.
7.1.2 Recognise that a woman and/or family member may have expertise about a particular genetic condition.	7.2.2 Utilise reliable genetic/genomic evidence when communicating with women and their family.	7.3.2 Develop effective communication strategies to inform women, families and colleagues of relevant genetic/genomic information.	Provide guidance to women and colleagues in sourcing and selecting credible and appropriate genetic/genomic information.
7.1.3 Describe the roles of key members of multi-disciplinary and multi-agency teams involved in the care of people with genetic/genomic healthcare needs.	7.2.3 Discuss how expertise within the family can inform ongoing care.	7.3.3 Promote a partnership approach with the woman and/or family members as appropriate to ensure optimal care	Demonstrate effective communication skills when discussing genetic/genomic information with women, their family and colleagues.
	7.2.4 Discuss how a multi-disciplinary and multi-agency team might interact in providing care.	7.3.4 Utilise the expertise of the women and/or family members to gain knowledge and understanding of a particular genetic condition for self and others.	Actively seek advice from the woman or family members to address care needs.
		7.3.5 Promote effective interaction within a multidisciplinary team to coordinate care.	Demonstrate ability to work in partnership with families.
			Recognise own role and contribute effectively within a team.

